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Breast-cancer risk turns more women to preventive mastectomy

By Barbara Isaacs - McClatchy Newspapers Published 12:00 am PST Sunday, November 12, 2006

Unless you are Dr. Julie Miller or someone like her, it's hard to imagine lying down on a surgical table to have your two healthy breasts removed.

But until that day in 2004, Miller, then a mother of an infant and a toddler, had lived in fear of breast cancer.

Her mother, who raised her alone, was diagnosed with breast cancer at age 46, while she was pregnant with Miller.

"My whole life, she was always updating her wills," Miller said. "It's something that's always been a part of my life."

Her grandmother and other relatives also battled the disease.

Miller, 37, is a radiologist who specializes in breast imaging at Kentucky's Central Baptist Hospital, so she knows about breast cancer and ways to prevent it.

Her decision was based on her strong family history of breast cancer, her work with breast cancer patients and being the mom of Alex, 4, and Grace, 3.

"I felt like I was waiting my turn," Miller said of breast cancer. "I needed to get that weight off my shoulders. I needed peace of mind and as close to an assurance as I could get." It might seem a drastic measure, but preventive mastectomy has been shown to reduce the chance of future breast cancer by at least 90 percent.

Though still not common, there's a growing demand for preventive mastectomy. Mostly it's due to genetic testing, now a decade old, that can identify two genes, BRCA1 and BRCA2, that put people at significantly higher risk of breast and ovarian cancer.

Hereditary breast cancer is thought to cause 5 percent to 10 percent of all breast cancers, said Heather Pierce, a University of Kentucky genetic counselor. It means that cancer-causing gene mutations are passed down in the family. Hereditary breast

cancer should be suspected when two or more close relatives -- mother, daughter, sister, aunt or grandmother -- have had breast cancer before age 50 or before menopause.

Women who have BRCA1 or BRCA2 are estimated to have a 60 percent to 85 percent chance of developing breast cancer by age 90. The gene mutations also have implications for men -- males who have the mutation are at higher risk of prostate cancer and male breast cancer.

Rachel Kelleher, a genetic counselor at Central Baptist Hospital, refers about seven people a month for genetic testing for the breast cancer mutations. And among the people who find they have the genetic flaw, 60 percent to 70 percent decide to have a preventive mastectomy, she said.

Kelleher said some national studies estimate that half of the women who find they have the breast cancer gene mutation choose mastectomy, usually followed by breast reconstruction.

She said many of those who choose genetic testing followed by preventive mastectomy are motivated by some of the factors that were key for Miller -- women of young children who have seen multiple family members battle breast or ovarian cancers.

"'I need to be here for my kids.' I hear that a lot," Kelleher said.

That was also the story for Missy Marrs, 29, a Lexington, Ky., real estate agent and appraiser.

Marrs' grandmother had breast and ovarian cancer and died at age 52. Her mother, Cissy Hart, was diagnosed with ovarian cancer at 54 and died in March at 56.

Marrs is married with two children, Andrew, 5, and Mary Keene, who is almost 3.

Marrs' mother underwent genetic testing and was found to have the BRCA1 gene. Then, Marrs and her sister were tested, and both of them had the gene as well.

"To me, it was a no-brainer," Marrs said of the genetic testing. "I needed to find out."

Marrs had a preventive double mastectomy in April and a second surgery for breast reconstruction in September. She said she's pleased with the results -- plastic and reconstructive surgeons do better work now than ever before, she said.

Because she's also at a higher risk for ovarian cancer, Marrs is planning to get a complete hysterectomy next month. Once her ovaries and fallopian tubes are removed, her risk of ovarian cancer is drastically reduced.

"I could have waited to have this done," Marrs said of the double mastectomy. "But I felt like I knew and let's just deal with it. There was no debate for me. I knew what I needed to do."

Kelleher, Marrs' genetic counselor, said that after both surgeries, Marrs will have a risk of breast and ovarian cancer that is lower than the general population.

"I can tell my children that I did everything I could do," Marrs said. "If I still get it, I'm sorry. I know it didn't start with me." Marrs said one thing she struggled with was making sure family members -- her husband and his family and her relatives -- were all on board with the idea.

"I was afraid they would think that I was overboard," she said.

"I didn't want people to judge me, that I'd gone haywire or off my rocker. I don't feel like I'm paranoid."

Miller, the radiologist who had a double mastectomy, hasn't undergone genetic testing, but she plans to someday. She said her family history was so riddled with breast cancer that she would have gotten her breasts removed no matter what the gene tests showed.

Testing, after all, does not tell the entire story. Some families have multiple cases of breast cancer but don't have either gene mutation.

Preventive mastectomy isn't the only strategy to deal with increased risk of breast cancer or a genetic mutation that can cause the disease. Pierce said that as a genetics specialist, she's equally comfortable with prevention by surgery or by increased screening in conjunction with cancer-preventing medication.

"There's lots of different options people have," Kelleher said. "Some people have the misconception that prophylactic mastectomy is the only choice."

Early detection efforts should be increased in high-risk women, including high-quality methods such as MRIscans of the breasts, digital mammograms or ultrasound exams. Some experts recommended breast MRI as the screening of choice for women with the BRCA1 or BRCA2 mutation, because those women are thought to be more likely to develop cancer if they are exposed to repeated radiation through mammography screening.

Also, traditional mammography is not considered the best choice for screening highrisk younger women, who have dense breast tissue that is difficult to screen with mammography.

The drug tamoxifen has been shown to reduce by 50 percent the chance of breast cancer in healthy women. Also, removal of the ovaries is recommended after childbearing is complete, because certain breast cancers grow more rapidly when exposed to estrogen, which the ovaries produce.

Testing for the breast cancer genes is about \$3,000 for the first family member and about \$300 for additional members of the family.

"Genetic testing doesn't change your risk," Pierce said. "What it does is provide the ability to make an informed medical decision." Pierce arranges for about 50 people a

year to get the testing. Some insurance companies will pay for the testing, depending on family history and other factors.

Marrs isn't just worried about her own future. She and her husband are in the process of forming a nonprofit group, the National Gene Test Fund, that would raise money to pay for genetic testing for high-risk individuals who don't have insurance coverage or means to pay for the test.

"My hope is that women out there with a strong family history, they need to get tested," Marrs said.

Still, the testing process can be painful emotionally.

"When I got the results, it hit me pretty hard," said Karen Bowles, 53, of Lexington, who has battled breast and ovarian cancers and had genetic testing. She has the BRCA1 gene mutation. "It was something terrible that I was probably going to pass on." But she is satisfied and assured that other family members know about it and can act on the information with increased screening.

"Any opportunity to do what you can to prevent something or stop something," she said, "why not do it?"